Siblings' Influence on the Development of Individuals with Down Syndrome

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Abstract

In this chapter, the influences that siblings may have on developmental outcomes of children with Down syndrome including those related to cognition, language, self-regulation, social-emotional functioning, and identity formation are discussed. As there is very little research available that addresses sibling influences on individuals with Down syndrome, the literature related to sibling influence within sibships comprising typically developing children has been used to provide a starting point to the discussion, with the hope that it will point to useful avenues for research. The few investigations that have been conducted suggest that siblings make an important contribution to developmental outcomes for individuals with Down syndrome.

Introduction

It is a truism that the sibling relationship is the longest relationship in one's life. While this relationship generally changes in fairly predictable ways across the lifespan, siblings typically remain connected to one another from birth until death (for a review, see Lanthier & Campbell, 2011). The intensity and longevity of this unique relationship means that it may play a central role across a number of life arenas. There is potential for this relationship to be more influential for children with Down syndrome than for children who do not have a disability, as their common experiences of social isolation and lack of acceptance in essential settings such as school (e.g., Schwab, Huber, & Gebhardt, 2016), may imbue considerably more potency to their interactions with their siblings.

This chapter is organised in four sections. The focus of the first is the roles that siblings of an individual with Down syndrome may play in relation to their brother or sister. The second section is focused on the research regarding the quality of the relationship between those with Down syndrome and their siblings. Relationships that are positive are likely to create more opportunities for influential interactions among siblings. The foci of the third section are areas of development of the individual with Down syndrome which may be open to the influence of siblings. The fourth section includes suggestions for research to advance our understanding of the mechanisms of influence that operate in sibships that include a member with Down syndrome, with the emphasis on the influence of siblings on the individual with Down syndrome. This chapter draws heavily on the research literature related to sibling influence in sibships involving only typically developing children to guide consideration of the potential mechanisms by which siblings influence each other's development and the areas in which sibling influence is likely to be most impactful. In order to avoid confusion, in this chapter, the term 'sibling' will always refer to the typically developing member of the dyad.

Developmental Impact of Siblings

Research with typically developing children has shown that siblings influence the development of their brothers and sisters in multiple ways and that these influences may be direct or indirect (Brody, 2004; McHale, Updegraff, & Whiteman, 2012). Direct influences occur as siblings take on the roles of playmate, model, and sparring partner, while indirect influences occur when siblings influence the ways in which the family operates, such as when parents change their ways of interacting with a second child, based on their experiences with their firstborn. While sibling influences will, in part, be extensions of parental influence (e.g., parents set the 'tone' of family interactions), siblings make a unique contribution to the developmental outcomes of their brothers and sisters. As an example, Padilla-Walker, Harper, and Jensen (2010) found that affection between siblings was predictive of a range of positive outcomes, including prosocial behaviour and self-regulation, and that these associations were still apparent after the quality of parent-child relationships were accounted for.

Much of the research about the influence of siblings on developmental outcomes has been focused on structural aspects of the sibship, including number of siblings, sibling position (older vs younger), and gender composition. The impact of these structural variables may differ, depending upon the aspect of functioning being considered and they may not apply when one member of the sibship has Down syndrome. In sibling dyads with two typically developing members, there are somewhat predictable dynamics between the members, especially during the childhood period, but these are often overturned when one child has Down syndrome. As an example, in sibling dyads where both members are typically developing, the older child is usually the leader and is imitated by the younger sibling (Howe, Rosciszewska, & Persram, 2018), whereas when children with Down syndrome are the older

member of the dyad, they are likely to be the imitator of their younger sibling (Gilmore, Ryan, Cuskelly, & Gavidia-Payne, 2016).

Siblings might be construed as a resource for their brothers or sisters as they can teach about the world, either explicitly or through being observed (Brody & Murry, 2001) and through their interactions with their brother or sister when they co-operate, share jokes, play tricks on and argue with them (Chen, 2015). They may play a particularly important role for children with Down syndrome as they appear to be the drivers of interactions. In observational studies, Knot, Lewis, and Williams (2007) and Singh, Iacono, and Gray (2015) found that siblings were significantly more likely to initiate interactions with the child with Down syndrome than vice versa. Whereas Singh et al. (2015) collected data at one time point only, Knott et al. (2007) collected data on two occasions, 12 months apart. In Knott et al.'s (2007) study, the siblings initiated both positive and negative exchanges at almost twice the rate of their brother or sister with Down syndrome at both time points. Knott et al. (2007) suggested that the siblings were often the architects of interactions within the dyad - their initiations increased dramatically over the year which provided increased prompts for responses from the child with Down syndrome.

While siblings themselves may be a resource, they reduce the parental resources available to the other children as parents will have less time to spend with each child the more children there are in the family (Lawson & Mace, 2009; Marjoribanks, 1991). Financial resources are also reduced. Reduction in these resources may impact negatively on outcomes, such as academic achievement (Schmeer, 2009) and health (Lawson & Mace, 2008), although thes affects are likely to be mitigated by the initial level of resources available in the family. Alternatively, competition for resources could result in skill development as children strive to meet their individual needs (Bjorkland & Pelligrini, 2011). To add to the difficulties in understanding sibling impacts, there may be different outcomes

according to family position. As an example of this, Lawson and Mace (2010) found a negative impact on mental health for those who were older in larger sibships but positive impacts for those who were younger. Clearly, there are many complexities around the mechanisms by which siblings influence each other and these may differ depending upon both the aspect of development being considered and the developmental stages of the children in the sibship.

Influential Roles.

There are a number of potential roles to be filled by siblings in a family with a child with Down syndrome. I shall not be exhaustive here, as all are speculative at the moment; however, I have generally chosen to focus on roles for which there is evidence in typically developing dyads, such as teacher, model and social referent, friend, foe, and contrast. The exception is the role of advocate, protector, and carer which may be found in sibships that include an individual with a disability but is not usually considered in the literature on typically developing sibships. All but this last role have been shown to be influential in child development in typically developing children and so may prove productive in understanding – and perhaps intervening in – the developmental trajectories of children with Down syndrome. The developmental impact of siblings will be influenced by the nature and level of engagement between them and their brother or sister, discussed further below, as well as by the personal characteristics of both members of the dyad.

Teacher.

Children generally learn a great deal from their siblings, and while both younger and older siblings engage in teaching, older siblings undertake more teaching than their younger brothers or sisters (Abuhatoum, Howe, Della Porta, Recchia, & Ross, 2016; Howe, Della Porta, Recchia, Funamoto, & Ross, 2015). They provide explicit instruction, with this

responsibility being observed in widely differing cultures (e.g., Rabain-Jamin, Maynard, & Greenfield, 2003). While sibling instruction will often be helpful, teaching that is too directive (i.e., not responsive to the needs of the child being taught) may undermine learning. Directive parenting has been found to be associated with reduced persistence in children with Down syndrome (Gilmore, Cuskelly, Jobling, & Hayes, 2009), and in a study of teaching in typically developing dyads, Howe, Recchia, Della Porta, and Funamoto (2012) found that directive teaching by a sibling led to disengagement from the activity by the learner partner.

There is a danger that siblings will engage in relatively high levels of directive behaviour when teaching their brother or sister with Down syndrome. The siblings of children with Down syndrome were found to be significantly more likely to engage in interactions that were unequal (i.e., teaching, managing, helping) than children whose younger brother or sister was typically developing (Stoneman, Brody, Davis, & Crapps, 1989) and to be more directive in their communications (Singh et al., 2015). This is consistent with Floyd, Purcell, Richardson, and Kupersmidt's (2009) findings that the siblings of children with intellectual disability were more directive toward their brothers and sisters than were siblings of children who were developing typically. In Floyd et al.'s (2009) study, the siblings of the children with intellectual disability gave three times the number of commands to their brother or sister than they received, whereas the number of commands was relatively equal between the pair in the dyads in which both children were developing typically.

One reason that siblings may be more directive is that they perceive their brother or sister with Down syndrome to be relatively incompetent – for example, their language skills are likely to be poorer than those of age peers at most ages (Cuskelly, Povey, & Jobling, 2016). Klein, Feldman, and Zarur (2002) found that children's approaches to teaching were influenced by their beliefs about competence and they were more likely to draw on a smaller

range of approaches to teaching with those they saw as less capable as opposed to more able. However, certain sibling characteristics may lessen the likelihood that they will adopt a directive approach to teaching, as those who are more sensitive to the needs of their brother or sister display more flexibility in their approaches to teaching (Prime, Perlman, Tackett, & Jenkins, 2014).

Some children are more sensitive to their brother's or sister's difficulty than are others, a characteristic that has been labelled 'cognitive sensitivity' by Prime et al. (2014). Children with high cognitive sensitivity adjust their teaching to accommodate the abilities and knowledge of their sibling, for example by simplifying instructions or providing a demonstration, whereas those with low cognitive sensitivity might merely repeat the original instructions. This ability and willingness to be flexible in interactions has been observed in typically developing children. For example, Howe, Brody, and Recchia (2006) found that children used more demonstration and scaffolding with more difficult tasks when teaching their younger sibling and also employed more strategies with younger children. Cognitive sensitivity is likely to be useful if it means that sibling assistance is pitched at the correct level to enable the learner to improve in performance (referred to as working within the zone of proximal development (Vygotsky, 1978)). However, if awareness of their brother's or sister's difficulty results in overprotectiveness or intrusive assistance, it may undermine the other's motivation and/or learning.

While the roles of teacher and learner are common in sibling interactions, this role sometimes becomes formalised in cases where one child has a disability. There have been a number of intervention studies in which siblings have been included as intervention agents (see, Kim & Horn, 2010 for a review not specific to children with Down syndrome). As an example, Trent, Kaiser, and Wolery (2005) taught the older siblings of two girls with Down syndrome to use responsive behaviours when interacting with their sister with Down

syndrome. Both siblings adopted the new behaviours and there were positive changes in the targeted behaviours of the young girls with Down syndrome. Recruiting siblings to the role of change agent may have unintended consequences, however. Having them take the role of teacher (at others' instigation) may emphasise the difficulties of the child with Down syndrome, increase perceptions of incompetence, and entrench directiveness in sibling interactions. Some consideration of these potential consequences needs to be built into interventions studies that use siblings as the agent of change, at least until researchers are certain that no inadvertent harm is caused.

Model and social referent.

Children also learn from their siblings by observing them as they solve practical and social problems (e.g., Watson, Meeks, Dufrene, & Lindsay, 2002; Wishart, 1986). Siblings will be more effective models than adults with respect to many tasks as children are more likely to be influenced by those they see as similar to themselves (e.g., other children) than they are by those they perceive to be dissimilar (e.g., adults) (Bandura, 1986; Barr & Hayne, 2003; Miltenberger, 2001). Modelling is the term most often used when discussing learning new skills through observation, but children also use others to provide information about how to respond to novel situations (e.g., with fear or openness) and how to manage their emotions. Sometimes known as social referencing, this can be seen in both immediate and deferred imitation, and may contribute to the similarities observed in the behaviours of siblings.

Imitation is one of the most important ways in which children learn from their siblings and is considered to be a relative strength for children with Down syndrome (Wright, Lewis, & Collins, 2006). Children with Down syndrome have been observed to use imitation in social and other situations (Wright et al., 2006), and have been found to be more likely to imitate their sibling than vice versa, regardless of whether they are the younger or older

member of the dyad (Abramovitch, Stanhope, Pepler, & Corter, 1987). Knott et al. (2007) interpreted imitation by the child with Down syndrome as a strategy for maintaining the sibling interaction, and this view is supported by the finding reported by Howe et al. (2018) that imitation leads to increased warmth between TD siblings. Thus, imitation may well have multiple functions, including relationship building and developing competence. However, Cebula, Moore, and Wishart (2010) cautioned that imitation and social referencing may not always be used effectively by children with Down syndrome. They pointed to evidence that children with Down syndrome often choose to use imitation when a different strategy would be more appropriate for dealing with the problem confronting them, perhaps because social relationships are more motivating than other aspects of the problem situation. With respect to social referencing, Cebula et al. (2010) cited evidence that children with Down syndrome use 'looks' to their parents less frequently than typically developing children. If this relative reduction in social referencing extends to others, including siblings, then the skills of children with Down syndrome will be diminished with respect to responding to situations in socially expected ways.

Friend and foe.

As in dyads where both siblings are developing typically, some sibships will generally be more amicable than others; however, all are likely to have times of harmony and of conflict. The impact of these relationship qualities on outcomes will largely be indirect as they act to amplify or decrease the effectiveness of the sibling as a teacher, model, and social referent (Whiteman, McHale, & Crouter, 2007). Siblings who have a positive, warm relationship are likely to choose to spend more time together than are those who experience a high degree of conflict (Noller, 2005) and are also likely to be more effective in the modelling role (Whiteman, Bernard, & McHale, 2010; Whiteman & Christiansen, 2008). Conversely, in

cases of destructive conflict, siblings will avoid each other, thus lessening the opportunity for influences to flow between the members of the dyad.

High levels of conflict in the sibling relationship have been shown to be associated with poorer outcomes in social competence (Stormshak, Bellanti, & Bierman, 1996) and child adjustment (Dirks, Persram, Recchia, & Howe, 2015). Although children with Down syndrome are not exposed to more conflictual relationships with their brothers and sisters than are other children (Cuskelly & Gunn, 2003; Fisman, et al., 1996), they are likely to experience some conflict with their siblings. Conflict is a normal part of the sibling relationship and can co-exist with warmth. Conflict may be characterised as constructive or destructive (Howe, Rinaldi, Jennings, & Petrakos, 2002). Constructive conflicts are of low intensity and differences can usually be settled by negotiation while destructive conflicts are generally of high intensity, and resolution is likely to be through the use of power strategies such as coercion. An absence of *constructive* conflict in the relationship may reduce opportunities for the development of certain skills, such as negotiation, compromise and understanding others' perspectives. This is supported by Floyd et al.'s (2009) finding that children with intellectual disability showed better social competence when their relationship with their sibling was characterised by either high warmth *or* high conflict. These findings suggest that both prosocial and constructively conflictual interactions between siblings will benefit the development of children with Down syndrome (see Kramer, 2014 for a review focussed on typically developing children).

Contrast.

One of the processes by which typically developing children develop the self that they present to the world is known as deidentification and involves differentiating themselves from their sibling. This process is seen to be particularly relevant for younger siblings as

they attempt to carve out a niche for themselves that differs from that occupied by their older brother or sister. According to theories of deidentification, the process protects younger siblings from direct competition with their sibling and from the negative emotion that will sometimes be the consequence of upward social comparison, as occurs when children decide that someone else is better than they are in a certain respect (Whiteman et al., 2007).

Investigations of the role of siblings in helping to establish a 'self' requires a developmental perspective as the roles that siblings play generally change with respect to how individuals understand themselves as they mature. With increasing age, differences in ability diminish and 'roles' become more solidified. The trajectories of these changes are likely to differ in families with a child with Down syndrome. For example, the gap in competence between siblings will widen rather than narrow as both cognition and language develop at a slower rate in children with Down syndrome than in children who are typically developing (Couzens, Cuskelly, & Haynes, 2011; Cuskelly, Povey et al., 2016). In some dyads in which the child with Down syndrome is older, there may be a crossover period as the younger sibling becomes the more capable. Thus, the processes of deidentification, with respect to the individual with Down syndrome, may be less intense than in typically developing children when the child with Down syndrome is younger, or more intense if they are the older child in the dyad.

There is some evidence that siblings are used for comparison purposes by individuals with Down syndrome, with parents reporting they were the most commonly used comparator (Cuskelly & Gordon, 2011; Glenn & Cunningham, 2004). Parents in the Glenn and Cunningham (2004) study reported that many of the young people in the study did not make downward (positive – 'I am better') or upward (negative – "I am worse') comparisons with respect to their sibling but made explicit or implicit 'lateral' comparisons where they described themselves as similar to, or wanting to be like, their sibling. The role that siblings

play in the development of self-understanding of those with Down syndrome is a question that requires further investigation.

Advocate, protector and carer.

Siblings may take on a number of social roles in the lives of their brother or sister with Down syndrome. These have the potential to influence the quality of life experienced by the person with Down syndrome but are unlikely to impact on developmental outcomes directly. Examples include the roles of advocate, protector, and carer. Acting as an advocate can occur during childhood as siblings assist their brother or sister to negotiate the complexities of playgrounds and school (Skotko & Levine, 2006). This role may become more formal as their brother or sister moves into the adult service system and decisions are made regarding occupation, housing, and health related matters. When discussing these concerns within the family, siblings may also take the role of advocate for their brother or sister if there are generational disagreements about what is possible and/or appropriate for the adult with Down syndrome. While the protector role has elements of advocacy attached to it, it is likely to be more personally demanding of siblings as it requires direct intervention including possible confrontations as siblings protect their brother or sister from taunts and unkindnesses from others (Skotko & Levine, 2006). Siblings have reported that they worry that their brother or sister will have unpleasant social experiences even though the vast majority also reported that their own friends were accepting of their brother or sister with Down syndrome (Skotko, Levine, & Goldstein, 2011).

Although siblings' contributions to the caregiving of their brother or sister with Down syndrome are not generally demanding during childhood (Cuskelly & Gunn, 2003), this may change as family members age. In Carr's (2005) longitudinal study of families with a child with Down syndrome in England, approximately 25% of mothers of adults with Down

syndrome expected that the adult would live with a sibling, although the siblings themselves did not report on their intentions in this study. In a more recent study in Australia, plans to take a substantial caregiving role in adulthood were reported by a large proportion of young adult siblings (Cuskelly, 2016), although only some of these siblings expected to have the same level of responsibility as was taken by their parents. In an earlier North American study of adult siblings of individuals with intellectual disability (not specifically Down syndrome), Greenberg, Seltzer, Orsmond, and Krauss (1999) found higher rates of intention to take on primary caregiving responsibilities than those reported by either Carr (2005) or Cuskelly (2016). The differences apparent in these studies may reflect changes over time to social and family expectations about sibling responsibilities, may relate to the different ages of sibling respondents, or may reflect some aspect of family functioning related to Down syndrome (see Hodapp & Dykens, 2012 for a discussion). There may also be country-based differences that reflect the type, quality and accessibility of adult social services as well as cultural differences with respect to familial obligations.

The increasing longevity of adults with Down syndrome is likely to lead to changes in sibling roles as their brothers or sisters accompany them into old age (Hodapp, Burke, Finley, & Urbano, 2016). Of particular note in this regard are changes to health as adults with Down syndrome live longer than ever before. There is evidence of vulnerability to mental health problems in late adolescence and adulthood (Dykens, et al., 2015; Mallardo, Cuskelly, White, & Jobling, 2014) and to dementia in middle to older adulthood (McCarron, et al. 2017; Stancliffe et al., 2012). See Capone (this volume) for further discussion. The sequalae of these illnesses may place increased demands on siblings to take an active role in the care and management of their brother's or sister's affairs, particularly as their parents age or experience ill-health or death.

The Quality of the Sibling Relationship.

The quality of the sibling relationship may act to magnify or diminish the developmental impact of siblings as it forms the context in which influential interactions occur. The sibling relationship determines, to some extent, the amount of the time the members of the sibship spend together and the nature of interactions between them. Most investigators of the relationship between individuals with Down syndrome and their siblings have reported that they are warm with low levels of conflict, regardless of whether the parents (Cuskelly & Gunn, 2003; Roper, Allred, Mandleco, Freeborn, & Dyches, 2014; Skotko, Levine, Macklin & Goldstein, 2016) or the siblings (Cuskelly & Gunn, 2003; Kaminsky, & Dewey, 2001; Pollard, Barry, Freedman, & Kotchick, 2013; Skotko et al., 2016) are the respondents. While positive relationships are the norm, not all children appear to share a positive relationship with their brother or sister with Down syndrome (e.g., Cunningham, 1996). In a study of 105 Korean mothers with a child with Down syndrome between the ages of 1 and 21 years and a typically developing sibling between the ages 4 to 19 years, Choi and Van Riper (2014) found that the mothers reported relationship difficulties between children with Down syndrome and their sibling. This is consistent with evidence from some other non-Western cultures that disability has different meanings from that attributed to it in the West (e.g., Grinker & Cho, 2013; Riany, Cuskell,y & Meredith, 2016), and these meanings will have an impact on the ways in which families, including siblings, respond to the individual with disability. Non-Western cultures are not all alike, of course, and even within a group of East Asian countries, Choi and Van Riper (2017) found different family responses to the presence of a child with Down syndrome.

In a study of the sibling relationship in adulthood, Cuskelly (2016) found that the siblings reported their relationship with their brother/sister to be moderately warm with low levels of conflict. Using an on-line questionnaire, Hodapp and Urbano (2007) also investigated adult relationships and found that siblings' reports of the relationship were very

positive. Using a 6-point Likert scale (6 = most positive), item scores related to relationship quality ranged from 4.78 to 5.39. Hodapp and Urbano (2007) reported that the level of warmth of the relationship reduced as the members of the sibship moved into middle age, although the study was cross-sectional rather than longitudinal.

This reduction in warmth reflects that seen in dyads where both members are developing typically (Lanthier & Campbell, 2011). One explanation may be that contact reduces as adult siblings move into middle age as found by Hodapp and Urbano (2007), a finding that mirrors relationship changes in sibling dyads in which both members are developing typically (White, 2001). A positive association has been reported between contact and the warmth of the sibling relationship in sibling dyads with a member with Down syndrome (Cuskelly, 2016; Hodapp & Urbano, 2007). Correlational associations are not causal, of course, and reductions in the frequency of contact and in sibling warmth may be the product of other variables. Middle adulthood is a very demanding life stage as offspring generally require a great deal of parental time and attention, and these demands may account for the observed reduction in contact and contribute to reduced emphasis on the relationship with siblings. As children mature to adulthood and move out of the parental home, contact between siblings of the parental generation often increases (Lanthier & Campbell, 2011), and these fluctuations may also occur in sibships with a member with Down syndrome.

Longitudinal studies are the most informative for understanding the natural history of sibling relationships and Janet Carr's longitudinal study of families of child with Down syndrome provides some information relevant to sibling relationships in adulthood. Janet Carr's population-based (a specified geographical area in England) longitudinal study of children with Down syndrome and their families was first described in 1975. In 2005, when the individuals with Down syndrome were 35 years old, she reported on contact between the adults with Down syndrome and their siblings. Based on maternal reports, she found that the

siblings of 35-year-old adults with Down syndrome had substantially more contact with their brother or sister than did comparison siblings at the same age, although no information was available about whether the level of contact had changed over time as is usual in typically developing sibships.

A relationship, by definition, involves at least two parties; however, the studies of the relationship between individuals with Down syndrome and their siblings have generally only included the voice, or data, of the siblings. Only two studies were identified in which individuals with Down syndrome were asked to provide their perspective of the sibling relationship. Using the same method and instrument, Skotko et al. (2011) collected data from individuals with Down syndrome in the United States and Wakai et al. (2018) collected data in Japan. Skotko et al. (2011) developed the instrument and undertook a number of steps to ensure its reliability and validity for use with persons with Down syndrome; nonetheless, some individuals with Down syndrome still needed to be excluded from both studies as they were unable to understand the questions and/or the response choices. The participants in the study in the United States included 284 persons between the ages of 12 and 51 years (M = 23.4 years), and the participants in the study in Japan included 74 participants over 12 years of age. While Wakai et al. (2018) did not provide details of the average age of their sample, the Japanese sample was clearly older than the American group. The majority of respondents in both studies said they liked their sibling (USA 97%; Japan 85%) and that they felt their sibling was a good friend (USA 89%; Japan 67%). In the American study, those with more siblings were more likely to endorse this latter item. The percentages of Japanese individuals with Down syndrome agreeing with the positive statements about their feelings toward their siblings were significantly lower than in the sample from the USA (Wakai et al., 2018). Cultural differences were hypothesized to account for other differences between the two groups but no speculations were made about the differences with respect to sibling

relationships. The associations between age and sibling relationships was not examined in either study, although this is a potential source of variation.

Aspects of Development Likely to be Influenced by Siblings.

Developmental areas in which siblings may have an impact include cognition and language, self-regulation, social-emotional competence, and identity formation. None of these areas develops in isolation from the others of course; for example, language experiences are central to social understanding (Milligan, Astington, & Dack, 2007) and both are important for social skill development (Girard, Pingault, Doyle, Falissard, & Tremblay, 2017; Mazza et al., 2017). While recognising that these developmental domains are inter-related, for clarity they will be considered separately in the following discussion.

Cognition and language.

Cognitive development and academic skills have been the subject of substantial investigation with respect to the influence of siblings in typically developing children. However, this interest has generally focussed on structural aspects such as number of siblings and birth order, rather than on the processes that might influence these. According to the Resource Dilution model (Blake, 1981; Downey, 2001), cognitive development is negatively affected by sibship size, as children with more siblings have lower achievement and children who are born later also fare more poorly (e.g., Steelman, Powell, Werum, & Carter, 2002). This association is explained by the reduction in parental resources available to individual children. For example, Workman (2017) found that older children received less parental time (e.g., storytelling and child-care activities) when a new child was born into the family. In an investigation of this model at older ages, Jensen, Whiteman, Bernard, and McHale (2017) found that 77% of the second born children in their study reported an increase in parental attention or material resources a year after the first born child left home (e.g., to attend

college). Children who reported increases in paternal time also reported increased interest in maths and their achievement was significantly higher than in the previous year. There was a similar increase in interest in language arts subjects for those who reported an increase in maternal time but no corresponding improvement in grades.

A recent investigation of the Resource Dilution model by Osmanowski and Cardona (2016) found some evidence to support the model in families with children who were typically developing; however, it did not apply in all families. In single-child families, the birth of a second child increased maternal activities with the firstborn; in multiple child families, an additional child decreased maternal activities. These contrasting effects indicate that siblings may act to positively or negatively impact on the resources available, depending upon other family circumstances. One possibility in families who have a child with Down syndrome is that having multiple siblings may augment the capacity of a family to support the development of a child with Down syndrome through increased direct teaching, modelling, and providing practice in negotiation.

Changes in the average size of families in the developed world may render the question of the impact of the number of siblings on child development less compelling to researchers in these countries; however, not all children across the globe are born into small sibships. In addition, a focus purely on number of siblings overlooks the processes by which certain outcomes come about and the Resource Dilution model provides one hypothesised mechanism. While no research has been conducted on these issues in families of a child with Down syndrome it is an area that may be fruitful in understanding the impact of siblings and parental practices.

Sibling influence on the language development of typically developing children is unclear - some researchers cite benefits (Benigno, Clark, & Farrar, 2007) and others report

negative impacts (Tompkins, Farrar, & Guo, 2013). This is somewhat surprising as it might be expected that language would be positively influenced by the presence of siblings due to the multiple opportunities for interaction that they provide. Understanding the impact of siblings on the language of children with Down syndrome would be very useful as this area of development is an identified area of difficulty for them (Abbeduto, Warren, & Connors, 2007; Lee, et al., 2017).

Self-regulation.

The ability to manage one's own behaviour in pursuit of goals has been labelled self-regulation. It is a complex construct with multiple components and might be considered to be an umbrella term that incorporates a range of capabilities, including executive functioning, which need to be integrated to support effective performance across developmental domains (Lynn, Cuskelly, O'Callaghan, & Gray, 2011). Self-regulation develops as children mature and become increasingly able to set their own goals and to control their emotions and behaviours in pursuit of these. Cuskelly and colleagues (Cuskelly, Einam, & Jobling, 2001; Cuskelly, Gilmore, Glenn, & Jobling, 2016) have examined self-regulation in individuals with Down syndrome using the delay of gratification paradigm developed by Mischel and Baker (1975) in which individuals are asked to wait for a self-selected goal in the presence of an immediate, tempting alternative. Persons with Down syndrome appear to have a particular difficulty in self-regulation, over and above that caused by intellectual disability, with language problems being hypothesised to be a contributing factor (Cuskelly, Gilmore et al., 2016). While there were significant differences at the group level, some individuals demonstrated that they were able to self-regulate, waiting for 15 minutes to achieve their goal. The interactions that are a natural part of sibling relationships, along with the consequences for family routines that follow from having to accommodate the needs of more individuals, may act to assist with the development of self-regulation. Siblings with whom

one needs to share, wait for, and resolve conflicts provide practice, models, and external support (e.g., parental instructions) for the multiple skills that contribute to self-regulation. This conjecture regarding the benefits of siblings in developing self-regulation is supported by studies of typically developing children (e.g., Brody & Murry, 2001; Downey & Condron, 2004) with these benefits lasting well into the school years (Downey, Condron, & Yucel, 2015). Downey et al. (2015) followed up 11,820 children initially seen in Kindergarten when they were in fifth grade. Teachers provided the data on self-regulation. Children with one sibling increased their self-control more than those without siblings across the period and existing deficits (observed at Kindergarten) between those with no siblings and those with one or more siblings remained even after 5 years of interactions with peers.

Social-emotional competence.

Social-emotional competence comprises a number of elements, including self-regulation of emotions and behaviour as well as understanding of self and of others, which contribute to how effectively children operate in the social world. While no published studies examining the impact of siblings on the social skills of children with Down syndrome were able to be identified, there are some studies that provide evidence of a positive association for typically developing children (Downey et al., 2015) and individuals with other developmental difficulties (Ben-Itzcak, Nachson and Zachor (2019). Hughes, McHarg and White (2018) provided a conceptual review of the ways in which siblings might contribute to the development of prosocial behaviour in their brothers and sisters.

Despite views that children with Down syndrome have relatively strong skills in social relationships, Cebula et al. (2010) have pointed out a number of areas of difficulty in social cognition. One example is difficulty in the recognition and understanding of some emotions (e.g., Pochon & Declercq, 2014; Virji-Babul, Watt, Nathoo, & Johnson, 2012).

These difficulties may be a barrier to positive peer and sibling relationships as children with Down syndrome may not respond as expected to expressions of emotion such as sadness (Hippolyte, Barisnikov, Van der Linden, & Detraux, 2009) and anger (Goldman, Shulman, & Burack, 2018). The experience of having siblings could be expected to improve children's understanding of emotion and there is some support for this expectation in families in which children are developing typically (Morand, 1999).

One central component of social-emotional competence, itself a multi-faceted, developmental construct, is theory of mind (ToM). ToM refers to the ability to 'read' others' minds – to understand, for example, that others may have beliefs about a situation different from one's own or may not actually mean what they have said. ToM incorporates a range of abilities that are linked to understanding the mental state of self and of others which become more sophisticated as children mature and new abilities emerge. Skills in ToM assist children to understanding others and thereby to effectively respond in a range of social situations (Cutting & Dunn, 2006), for example by recognising when a peer is joking or means what he or she is saying. Better ToM skills may also increase children's capacity to communicate about their own mental states, thus increasing their desirability as play mates. Social skills and ToM are positively correlated in typically developing children (Peterson, Slaughter, Moore, & Wellman, 2016; Weimer, Burleson, Stegall, & Eisenman, 2018). Investigations of ToM in children with Down syndrome provide evidence that ToM is more delayed than in children of the same mental age (Losh, Martin, Klusek, Hogan-Brown, & Sideris, 2012). While delayed, it does continue to develop (Amadó. Serrat, & Vallès-Majoral, 2016) and so may be open to influence by siblings.

Siblings are expected to be central to facilitating ToM because the relationship affords many opportunities for social interactions with a partner who is close in age. This repeated

exposure allows children to develop an understanding of the connections between individuals' behaviours and their feelings and thoughts (Carpendale & Lewis, 2006; Howe, Ross, & Recchia, 2011). Larger sibships are likely to provide a more enriched 'data base' than smaller sibships as they provide multiple different examples. Positive sibling relationships have been found to be predictive of ToM in typically developing children (Hughes & Ensor, 2005), presumably because of increased exposure to another's way of understanding the world. However, children also experience conflict in their sibling relationships and the negotiations required to resolve conflicts are also thought to contribute to ToM skills (Kramer, 2014). Older siblings have generally been found to benefit the development of ToM (Derksen, Hunsche, Giroux, Connolly, & Bernstein, 2018; Kennedy, Lagattuta, & Sayfan, 2015). One potential reason for this advantage is the increased cognitive talk to which children with older siblings are exposed (Jenkins, Turrell, Takai, Lollis, & Ross, 2003). The contribution made by siblings to the social-emotional competence of children with Down syndrome is an area ripe for exploration.

Identity formation.

The elements of a robust self-identity comprise understanding and acceptance of one's strengths and limitations (i.e., self-knowledge), and a positive sense of self. Individuals with Down syndrome generally have a positive self-image (see Deakin, Moore, & Jahoda, 2018; Glenn & Cunningham, 2001). Siblings contribute to identity formation through the direct and indirect feedback they provide and through their role in social comparison processes. They contribute to the development of an understanding of self, in part by providing an 'other', either to emulate or from which to try to differentiate (Davies, 2015; Wong, Branje, VanderValk, Hawk, & Meeus, 2010).

As most siblings feel warmly towards their brother or sister with Down syndrome (Skotko et al., 2006; 2016), they are likely to provide affirmative feedback in their daily interactions. Positive sibling relationships contribute to healthy and positive self-views in typically developing adolescents (Milevsky & Levitt, 2005) and this is likely to also be the case for individuals with Down syndrome. As discussed previously, some individuals with Down syndrome engage in social comparison, with siblings the most common person used for this purpose (Cuskelly & Gordon, 2011; Glenn & Cunningham, 2001) - there is a need to examine the contributions siblings make to the self-identify of their brothers and sisters with Down syndrome.

Directions for Future Research

The need for theory driven research with respect to sibling influences on children with Down syndrome has been pointed out by Cebula et al. (2010). Bronfenbrenner's bioecological model of development (Bronfenbrenner, 2001; Bronfenbrenner & Morris, 2006) offers a useful overarching theory to guide research in this area as it focusses on children's proximal interactions (i.e., those that occur frequently and repeatedly) as the most important influences on development. The idea that sibling interactions are crucial drivers of development clearly fits well with this model which also acknowledges the role of biological characteristics in influencing development. Thus, the model is able to accommodate the proposal that the characteristics associated with Down syndrome may elicit certain behaviours on the part of social partners (Hodapp & Dykens, 2012) as well as the possibility that certain aspects of development may be resistant to external influences. The bioecological model is able to encompass the impact of culture on the nature of sibling interactions and potential changes over time. In addition, other frameworks, such as the Resource Dilution model with its focus on the number of siblings in the family (Downey, 2001) and changing impact of this family characteristic (Zajonc, 2001), and the role of indirect influences are able to be encompassed

by Bronfenbrenner's broad theoretical model and may contribute a useful lens to understanding some of the links between siblings and the developmental outcomes of individuals with Down syndrome.

There are many challenges to undertaking research on sibling contributions to developmental outcomes as Down syndrome is a low incidence condition with considerable within group variability, including in areas of cognitive ability (e.g., Channell, Thurman, Kover, & Abbeduto, 2014) and language (e.g, Kaat-van den Os, Volman, Jongmans, & Lauteslager, 2017). A substantial proportion on children with Down syndrome have additional diagnoses as they are at risk of visual (Duckman, 2014) and hearing problems (Nightengale, Yoon, Wolter-Warmerdam, Daniels, & Hickey, 2017), and to having co-morbid autism spectrum disorder (see, Reilly, 2009 for a review). These individual characteristics are likely to have some impact upon the influence of siblings on certain outcomes but may occur in a very small number of study participants.

Children with Down syndrome are born to parents in all socioeconomic groups, although research is somewhat hampered by the difficulty of recruiting and then maintaining families from across the entire spectrum, with reduced representation of families in the more disadvantaged groups (e.g., Couzens, et al., 2011). Studies that are focussed on sibling influences may also be affected by sampling bias as such studies may be more attractive to families in which the sibling relationship is positive than in those where the relationship is acrimonious.

Parental characteristics and behaviours are likely to play a crucial role in the nature of sibling interactions and relationships (see, for example, Dawson, Pike, & Bird, 2015; Kretschmer & Pike, 2009). Parents of a child with Down syndrome are often identified as having higher levels of stress than parents whose children are developing typically, and as

parenting somewhat differently (e.g., Phillips, Conners, & Curtner-Smith, 2017). These aspects of family life should be incorporated into research on sibling influence as understanding the family context may help to explain variation in outcomes.

The indirect effects of sibling influence, through the impact on parental behaviour, also need to be considered, and these considerations need to incorporate the reciprocal influences of siblings and the child with Down syndrome. Potential foci include whether parents parent differently if they have a typically developing child who is older than the child with Down syndrome in contrast to when the child with Down syndrome is first born; and the impact of a child with Down syndrome on the way that mothers and fathers parent their other children.

Siblings acting as intervention agents can be effective in changing the behaviour of their brother or sister with Down syndrome (e.g., Trent et al., 2005); although these interventions may change the nature of the relationship between the members of the sibling dyad in ways that are not anticipated. Some changes may occur that are not positive. As examples, the increased responsibilities may increase sibling anxiety and involvement in an explicit intervention program may introduce the idea that the child with Down syndrome is incompetent, thus changing the types and nature of interactions between the siblings. Alternatively, there may be positive changes in the relationship or other benefits to the sibling such as increased skills. Some consideration of these potential outcomes needs to be built into intervention studies that use siblings as the agent of change until the consequences for both children in the dyad are established.

Investigations of sibling influence will, on occasion, require input from participants with Down syndrome in order to obtain a complete understanding of the phenomenon. The difficulties inherent in research that aims to do this are evidenced by Skotko et al.'s (2011)

attempt to develop an instrument to collect information from individuals with Down syndrome about their perspectives of the sibling relationship. Despite the rigorous approach in the construction of the questionnaire, some individuals were unable to respond due to their limitations in understanding the items. More needs to be done to ensure that there is a variety of methods appropriate to collecting information from as wide a range of persons with Down syndrome as possible. Without adequate data of their experience of sibling interactions and the impact of siblings on their behaviours from their perspective, we are limited in our understanding of the ways in which siblings impact on their development.

As almost all of the research discussed in this chapter is based in the United States, Great Britain, or Australia, we need to also examine these issues in other cultures where expectations and engagement of siblings differ from those usual in Western cultures. Sibling obligations differ between cultures (Lauderdale-Littin & Blacher, 2017) as do community interpretations and understandings of disability (Riany et al., 2016). Our understanding of the roles that siblings can and do play in the development of their brother or sister with Down syndrome will be greatly enhanced with the recognition and consideration of differing cultural meanings of disability and sibling responsibility.

As argued throughout this chapter, siblings are likely to be crucial influences on developmental outcomes for individuals with Down syndrome. However, the mechanisms by which siblings contribute to positive growth in their brother and sisters with Down syndrome may differ in important ways from those in typical sibships. There is very little research that has investigated these possibilities. This is an extraordinary oversight and one which demands the attention of researchers.

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